Behavior Inventory for Down Syndrome (BIDS)

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Introduction

- Need for sensitive outcome measures to measure clinical efficacy in clinical trials in DS (Esbensen et al., 2017).
- Fundamental gap in the availability of behavioral outcome measures that are appropriate, valid and sensitive to detecting change among children with Down syndrome.
- Without appropriate outcome measures, results from clinical trials or behavioral interventions may be difficult to interpret, and null findings could result from poor outcome measures, rather than from the ineffectiveness of the treatment.
- The objective is to create a parent report measure of maladaptive behaviors unique to children and adolescents with Down syndrome that is comprehensive, consensus-driven, informed by development and behavioral phenotype, and sensitive to treatment changes (BIDS - Behavior Inventory for Down Syndrome).

Methods

- Item Generation
  - Reviewed and categorized questions from 26 currently available standardized measures of behavior, adaptive behavior, and psychopathology.
  - Generated a priori themes and sample items to guide focus group discussion
- Focus Groups
  - 3 focus groups, 23 participants:
    - Parent/Expert combination: n=4
    - Parent of child 2-18 years with DS only: n=8
    - Expert only: n=11
  - Each focus group was approximately 2 hour in length
    - Are presented behaviors a concern among individuals with Down syndrome?
    - What aspects are significant?
    - Any aspects not mentioned that are of concern?
  - Themes
    - Focus group responses transcribed verbatim from audio recording.
    - Responses analyzed independently by three study staff for themes
    - Agreement established among study staff
  - Exhaustive list of potential items was developed by study staff to address themes.

Themes

Theme	Description	Sample Items
Noncompliance	Behaviors that relate to noncompliance.	• Actively resists by making his/her body limp • Bolts away from adults • Advocates strongly against activity
Repetitive Behaviors	Repetitive or self-stimulatory behaviors that impact daily function.	• Has habits that get in the way of doing things • Insists that items remain a certain way • Eats a restrictive diet
Executive Functioning	Behaviors related to executive functioning that impact on daily living skills.	• Has difficulty initiating familiar tasks without cueing • Gets lost easily in familiar places • Demonstrates a good ability to plan activities
Hyperactivity	Behaviors related to hyperactivity that impact daily function.	• Gets distracted easily • Acts impulsively • Demonstrates appropriate reaction to minor annoyance
Social	Behaviors related to social situations that impact daily function.	• Is resistant to meeting new people • Shows off at inappropriate times • Comforts strangers
Physical Aggression	Behaviors related to physical aggression.	• Spits at others • Harms self • Vocalizes in a threatening manner
Attention Seeking	Behaviors where the motive is to get attention placed on themselves.	• Self-advocates • Disrupts group activity • Uses inappropriate words
Anxiety	Behaviors related to anxiety that impact participation.	• Demonstrates anxiety with unplanned events • Hides behind caregiver in public • Exhibits panic attacks
Unsafe Behavior	Behaviors that put themselves or others at a safety risk.	• Engages in unsafe play • Seems to understand/recognize limitations or boundaries • Demonstrates little fear for personal safety

Other themes include: Wandering, Sleep, Hygiene/ADLs (Activity of Daily Living), Other

Pearls of Wisdom

- Include positively worded items and strengths of child
- Develop a separate teacher report version
- Capture frequency/duration/intensity of behavior
- Does function of behavior impact item generation?

- Items account for:
  - Developmental level
  - Communication skills
  - Comorbid health conditions
  - Physical skills
  - Executive functioning skills

Progress

- After the initial thematic analysis was complete, the content were revisited for a *second time* by study staff to reach agreement.
- If any content changes were needed, materials were rearranged under the established headings.
- Updated content were discussed to make sure information was consistent with the themes.
- An exhaustive list of 332 items was generated to fit within themes.
- List was sent to collaborator, Lina Patel, PsyD, Sie Center for Down Syndrome (Colorado), to identify any potential omissions.

Next Steps

- Refine items with Dr. Patel
- Delphi Method
  - Generate list of questions for expert panelists to evaluate each item
  - Submit questions into RedCap survey
  - Submit items to Delphi experts to refine BIDS items
    - Leonard Abbeduto, PhD UC Davis
    - Michael Aman, PhD, Ohio State University
    - George Capone, MD, Kennedy Krieger Institute
    - Frances Conners, PhD, University of Alabama
    - Deborah Fidler, PhD, Colorado State University
    - Sharon Krinsky-McHale, PhD, NY State Institute for Basic Research in Developmental Disabilities
    - Mary Pipan, MD, Children's Hospital of Philadelphia
- Develop companion teacher form
- Focus groups with self-advocates to support self-report version
- Online RedCap survey
  - 1200 parents of children of Down syndrome ages 2-18 years
  - Assess retest reliability
  - Assess respondent burden

Acknowledgement

We would like to thank the focus group members who participated, and the Jack H. Rubinstein Foundation.